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ABSTRACT

This report presents information developed from a workshop on the Inclusion of Language Minority Populations in National Studies (Bethesda, MD, July 17-28, 2000). To help find ways for survey research to capture the increasing linguistic diversity of the United States and thus be truly representative, this report focuses on current barriers to inclusion as well as ways to enable inclusion. Cost is the most significant barrier to including language-minority populations in national studies because of the costs of sampling and obtaining and using bilingual research personnel. Geographic distribution, language change over time, lack of coherence with research goals, and the use of community members as translators and interpreters are other barriers. New technologies and approaches are offering solutions to these problems. Cost can be decreased through innovative sampling approaches. The translation of survey instruments should incorporate and expand on several principles, which include the testing of translations with focus groups of monolingual speakers from the target research group. Researchers should build time for translations when designing and planning studies, and the increasing sophistication of machine technology can reduce the amount of time required for professional translators to refine and correct tests. Researchers should make optimal use of existing knowledge by building on the work of others and collaborating across disciplines. Four appendixes discuss examples of recent and current practice, the agenda from the conference on including language minority populations in national studies, a list of conference presenters, and a list of workshop participants. The Executive Summary is published in brochure form in both English and Spanish. (Contains 1 table and 26 references.) (SLD)

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Diverse Voices

The Inclusion of Language-Minority Populations in National Studies: Challenges and Opportunities

Editors
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National Institute on Aging
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The planning for this meeting began in 1999 when I was affiliated with the Demographic and Behavioral Sciences Branch (DBSB), National Institute of Child Health and Human Development (NICHD). When I joined the Behavioral and Social Research Program, National Institute on Aging (NIA) in 2000, I was able to continue working on this activity with the support and encouragement of the Associate Director, Richard Suzman. Fortunately, around the same time, Peggy McCardle, a linguist by training, joined the Child Development and Behavior Branch at NICHD. Peggy was willing and interested in taking the lead for NICHD in planning the meeting, and her rigorous thinking and managerial abilities soon became apparent. We were also fortunate to get reinforcements. Dan Berch joined NIA in the spring of 2000 and pulled together the session on technological innovation and linguistic logistics. We also recruited Rebecca Clark from DBSB shortly after she joined NICHD in early 2000. Her strong background in immigration research and her prior tenure at the Urban Institute helped us fill in many of the remaining holes in the agenda. We also benefited by earlier brainstorming sessions with Christine Bachrach, Chief of DBSB at NICHD, and Natasha Cabrera, a psychologist at NICHD. The final meeting agenda was truly strengthened as a result of this multidisciplinary collaboration and input.

Many people contributed time and expertise to the meeting and the writing of this meeting report. We appreciate the cooperation and assistance of all the meeting participants who provided valuable and stimulating comments. Nathan Stinson, Deputy Assistant Secretary for Minority Health, Department of Health and Human Services, and Yvonne Maddox, Acting Deputy Director of NIH and the Deputy Director for NICHD, graciously agreed to serve as keynote speakers. Their remarks underscored the relevance and timeliness of the topic in multiple arenas, from data collection to health care delivery. We are grateful to John Ruffin, Director of the NIH Office of Research on Minority Health since its founding in 1990, and now the Director of the NIH National Center on Minority Health and Health Disparities, for authorizing the funds that provided the catalyst for transforming the idea for this meeting into a reality. We want to give special thanks to April Burton at NICHD who helped with the logistics for the meeting, and coordinated with the folks at IQ Solutions to make the meeting a success.

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Rose Maria Li
August 2001

Diverse Voices

The Inclusion of Language-Minority Populations in National Studies: Challenges and Opportunities

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Executive Summary

In August 2000, President Clinton issued an Executive Order requiring all federally assisted programs to provide access for persons with limited English proficiency. This order highlighted the need to consider language issues in the design and execution of federal, state and local service programs. Concurrently, it stimulated awareness of the need for scientifically reliable data on the prevalence of English proficiency and the steps needed to overcome existing barriers to collecting such information.

Individuals in the United States who do not speak English well (referred to as language-minority individuals) represent a major challenge for health and social service agencies, educators, policy planners, and researchers. Although only about 3 percent of the U.S. population aged 5 and over speak English poorly or not at all, the proportion varies substantially by age, nativity, education, and other factors. Demographers and other social scientists usually use large-scale household surveys, based on probability sampling, to collect data that accurately represent the characteristics of the U.S. population as a whole. Most surveys limit their interviewing to English or English and Spanish, and respondents must have a relatively high level of proficiency in that language.

If, as expected, the proportion of language-minority individuals in the population increases over time, the representativeness of national samples is increasingly compromised. Indeed, population research based on what are purportedly nationally representative surveys very often will overlook those immigrants likely to be the most vulnerable. Since lack of language ability is often a barrier to accessing health care and other social services, the inability to speak English well may contribute to disparities in health outcomes.

In view of strong national commitments to (1) improving the inclusion of minorities in clinical trials; (2) reducing health disparities among subpopulations; and (3) developing cultural competence in health service delivery, researchers and policy makers should give added attention to language as a potential barrier excluding people from national surveys, as well as from access to health care and social services. To help find ways for survey research to capture the increasing linguistic diversity of the United States and hence be truly nationally representative, this report focused on current barriers to inclusion as well as ways to enable inclusion.

Barriers to Inclusion

A recurring theme throughout this report is that **cost is the most significant barrier to including language-minority populations in national studies**. Four necessary but expensive tasks were identified: (1) sampling to get sufficient numbers of subjects who do not speak English well; (2) translating or developing survey instruments (including the concomitant costs of vetting the translation, conducting focus groups, and/or piloting surveys); (3) recruiting, hiring, and training bilingual interviewers; and (4) contacting and interviewing subjects who live in rural or geographically diverse locations.

The geographic distribution of minority language populations may be a significant barrier to their inclusion in national studies. Language-minority individuals are often difficult to include in studies either because they are clustered in small, possibly remote areas, or because they are not concentrated in any particular area. Cost-effective sampling strategies based on geographic location therefore often cannot be used.

Language change over time is a barrier to inclusion of language-minority groups in research. The version of language spoken by recent immigrants often differs significantly from that of individuals who immigrated several years ago. And, among long-term immigrants, those who live in isolated communities develop different dialects from those who routinely interact with English speakers.

Lack of coherence with other research goals presents a barrier. Addressing specific language groups may not be well-integrated into a project's major research focus, and may therefore seem an ad hoc, add-on component that does not fit well with the overall research goals and design.

Use of community members as translators/interpreters may be a barrier. While the use of local translators and interpreters can sometimes improve survey coverage, their use also may be a barrier with regard to issues of confidentiality or culturally sensitive topics that respondents are uncomfortable with or reluctant to openly discuss with someone from their own community. Similarly, someone from the local community (either the current community or the community of origin of an immigrant) may invoke the class structure of the culture of origin, which can interfere with the goals of the research.

Enabling Inclusion

The challenges of including language-minority populations in national surveys and studies are not new, and many underutilized resources are already at hand. In addition, there are new technologies and potential solutions on the horizon. It is possible to **decrease cost through innovative sampling approaches**, rather than screening the general population. For example, researchers can identify subjects through pre-existing lists based on administrative records (e.g., birth registries, INS records, Medicare records). Other strategies include using telephone interviews to conduct preliminary screenings, and cumulating data from repeated surveys in order to increase sample sizes.

Instrument translation should incorporate and expand on several important practices. Translation should be done by professional bilingual translators, and the translations should be vetted (judged as to linguistic and cultural appropriateness) by monolingual speakers of the target language. Translated or parallel instruments should undergo cognitive testing to determine that they test/query the same concepts. Researchers should allow translation into Anglicized dialects. The retention/inclusion of English terms in the translated instrument is important when a concept does not exist in the target language and culture. Translations should also be tested in focus groups of monolingual speakers from or typical of the target research group, and should be piloted whenever possible.

Researchers should build in time for translations when designing and planning studies. The English version of an instrument should be completed before beginning its translation, and there must be time to translate, evaluate, and test the translated version prior to the initiation of actual data collection in either language. Alternatively, researchers could develop (or contract development of) a parallel, culturally appropriate instrument simultaneously with the English language instrument, or lagged behind the English version but overlapping in timing.

The rapidly expanding sophistication of **machine technology can reduce the amount of time required for professional translators** by allowing them to refine and correct translations rather than shoulder the entire translation burden. Although not applicable in all cases, some research should benefit from using one or more of the three major types of machine translation currently in use—knowledge-based, corpus-based, and human-in-the-loop.

In order to complement and inform future activities, researchers should ensure that they **make optimal use of existing knowledge by building on the work of others and collaborating across disciplines.** Researchers should:

- Gather and share the experience of international organizations that already have multilingual survey experience (e.g., United Nations, Organisation for Economic Co-operation and Development, World Bank, Demographic Health Surveys, World Health Organization).
- Archive translations and source texts to share and to combine with those of colleagues for potential use in machine translation memory databases.
- Use existing survey instruments as a starting point whenever feasible. For example, a survey from another country, already written in the language of that country, might require refinements to accommodate cultural adaptations that have taken place since a group emigrated, but could provide a basis to build on.

Diverse voci fanno dolci note;

così diversi scanni in nostra vita

rendon dolce armonia . . .

(Diverse voices make sweet music;

as diverse conditions in our life

render sweet harmony . . .)

Dante, Paradiso IV: 124-126

Introduction

By most estimates, the non-English speaking population in the United States is increasing. Growing levels of immigration are the single most important factor contributing to the overall size and internal diversity of the language-minority population. Because it is difficult to incorporate those who do not speak English or do not speak English well into national studies and surveys, this group is often not included in these research efforts. If the growing language-minority populations are excluded by default, the representativeness of national samples will become increasingly compromised. Therefore, it is prudent to pay attention to language as a potential barrier for inclusion in national surveys and studies, or for access to health care and social services. But because we know there are substantial costs associated with developing and validating research instruments in multiple languages, and in administering surveys in multiple languages, most studies limit their subjects to English speakers, or English and Spanish speakers. This would suggest that population research based on what are purportedly nationally representative surveys very often will overlook the presumably most vulnerable populations—those who don't speak English well. Since language ability is often a barrier to accessing health care and other social services, the inability to speak English well may contribute to disparities in health outcomes.

A number of questions and issues arise. Does a specific research initiative require the inclusion of certain groups and not others? Given that certain subpopulations have been defined as essential targets of study, which techniques are most likely to yield a statistically valid sample that accurately represents their characteristics? What are the barriers to inclusion of language-minority populations, and what can we do to improve the situation? How are current data collection efforts tackling language issues? These are preliminary questions in a research process that will require information from respondents who often do not share the language or culture of those conducting the research. In national data-collection initiatives, developing effective methodologies for establishing communication in the field is as vital to the success of efforts to include language-minority subpopulations as is the use of innovative sampling techniques.

To address these questions, representatives from the National Institute on Aging and the National Institute of Child Health and Human Development, with funding assistance

from the NIH Office of Research on Minority Health, convened a workshop on the Inclusion of Language-Minority Populations in National Studies. This report provides the outcome of that workshop, held on the NIH campus in Bethesda, MD, on July 27-28, 2000. In keeping with the multidisciplinary approaches fostered by both Institutes, participants in the workshop included demographers, statisticians, sociologists, psychologists, linguists, anthropologists, experts in emerging computerized translation technologies, representatives of major private survey organizations and translation agencies, opinion leaders, and representatives of Federal agencies (including the U.S. Census Bureau, the Centers for Disease Control, and the Office of Management and Budget, as well as the NIH and other entities within the Department of Health and Human Services).

On August 11, 2000, shortly after the meeting, then-President Clinton issued an Executive Order requiring all federally assisted programs to provide access for persons with limited English proficiency. This order highlighted the importance of language issues, and stimulated awareness of the need for and importance of scientifically reliable data that include individuals who speak little or no English. Without information on language-minority populations, it is impossible to assess their needs and access to various forms of assistance, including health care. As the text of the Executive Order states emphatically, equal access to federally sponsored programs is a basic civil right, regardless of whether an individual is a fluent English speaker.

Describing the Language-Minority Population

In 1990, almost 32 million individuals five years of age and older—13.8 percent of the United States population within this age bracket, or one out of every seven people—spoke a language other than English at home. While a majority (79 percent) reported that they possessed functional levels of English proficiency, more than 6.5 million revealed that they either did not speak English well or could not speak the language at all (U.S. Census Bureau, 1999). Because of continued high rates of immigration, these numbers likely have increased during the past decade. The magnitude of the continuing transformation of the linguistic profile of the American population will become more apparent when data collected during the 2000 Census become available.[1]

People aged 5 years and older who do not speak or understand English very well are referred to henceforth as language-minority individuals. The language-minority population is heterogeneous, stratified racially, culturally, socially, and linguistically. Patterns of geographic dispersion and large average household size of many language-minority subpopulations, including many Hispanic subgroups, often preclude the use of conventional, area-based household sampling procedures to capture language-minority populations. For equal numbers of minority and non-minority individuals within a given

[1] On August 6, 2001 the Census Bureau released Census 2000 Supplementary Survey Summary Tables for the U.S. documenting that 45 million individuals five years of age and older, which represent 17.6 percent of persons in this age group, speak a language other than English at home, up from the 13.8% reported in 1990. Of these 45 million individuals, more than 10.5 million or nearly a quarter, either speak English "not well" or "not at all."

primary sampling unit (PSU), fewer minority individuals will be registered by surveys because they occupy a smaller number of discrete household dwellings than do their non-minority counterparts. Disproportionate numbers of minority populations also live in group-based housing or in institutionalized settings, another factor that reduces their selection rates in conventional household-based surveys.

Compared with the general population, language-minority subpopulations contain disproportionately high numbers of vulnerable members of our society, including adults and children living in or near poverty, the less educated, and the elderly. Recent studies have demonstrated that individuals with low levels of English proficiency or who are linguistically isolated[2] often have greater than usual difficulties gaining access to medical care and other social services than do English speakers (Young et al., 1987; Zahn, 1999; Phua and McNally, 1999). A lack of proficiency in English may contribute to the disparities in health outcomes among some minority groups.

Extant Demographic Data on U.S. Linguistic Diversity

Data from the 1990 Census, although neither complete nor unambiguous, offer a valuable portrait of a key aspect of American linguistic diversity: the broad array of languages spoken by persons residing in the United States. The Census provides the relative distributions of languages over several major demographic categories (e.g., age and nativity) as well as information on the characteristics of language-minority speakers that may significantly influence aspects of survey design (particularly field protocols), such as relative levels of English proficiency, education, socioeconomic status, and the proportions of linguistically isolated households.

In the 1990 Census, Spanish speakers accounted for 54 percent of the 32 million individuals who reported speaking a language other than English at home[3] and slightly more than two-thirds of the language minority population, i.e., those who speak English "not well" or "not at all" (Table 1).[4] Among the remaining 15 million people who spoke a language other than English at home, no other single language dominated. The Census Bureau reported 380 languages and dialects spoken by respondents who spoke a language other than English at home. After Spanish, the next nine most frequently spoken languages were, in order of frequency: French, German, Italian, Chinese, Tagalog, Polish, Korean, Vietnamese, and Portuguese. Besides Spanish, only French, German, Italian, and Chinese

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[2] The Census Bureau defines a linguistically isolated household as one in which no person over the age of 14 speaks only English or speaks the language "very well."

[3] As a result of their relative numbers, Spanish speakers have proven easier than other groups to include in national surveys and studies.

[4] Among the elderly aged 65 and over who did not speak English well or at all in 1990, about 45 percent spoke Spanish, about 8 percent spoke Chinese, and about 7 percent spoke Italian (special tabulation by J. McNally of the Census PUMS 1/1000 file). On August 6, 2001 the Census Bureau released new 2000 Supplemental Survey Tables with updated estimates showing that Spanish speakers now account for 60 percent of the 45 million individuals who reported speaking a language other than English at home. Among the elderly aged 65 and over who did not speak English well or at all in 2000, about 50 percent spoke Spanish.

TABLE 1

People Who Speak a Non-English Language at Home and Who Speak English "Not Well" or "Not at All"

	Speak Non-English Language at Home	Speak English "Not Well" or "Not at All" (NELP)	Percentage of all NELP	Cumulative Percentage of NELP
Spanish	17,339,172	4,500,973	67.46	67.46
Chinese	1,249,213	373,216	5.59	73.05
Korean	626,478	188,419	2.82	75.88
French	1,702,176	157,724	2.36	78.24
Italian	1,308,648	151,262	2.27	80.51
Vietnamese	507,069	143,173	2.15	82.65
German	1,547,099	101,163	1.52	84.17
Polish	723,483	98,384	1.47	85.64
Portuguese	429,860	98,334	1.47	87.12
Japanese	427,657	91,096	1.37	88.48
Russian	241,798	65,304	0.98	89.46
Tagalog	843,251	63,028	0.94	90.41
Thai (Laotian)	206,266	57,843	0.87	91.27
Mon-Khmer (Cambodian)	127,441	54,663	0.82	92.09
Greek	388,260	44,035	0.66	92.75
French Creole	187,658	41,872	0.63	93.38
Armenian	149,694	38,700	0.58	93.96
Hmong	81,877	37,904	0.57	94.53
Arabic	355,150	37,492	0.56	95.09
Hindi (Urdu)	331,484	29,503	0.44	95.53
Persian	201,865	25,213	0.38	95.91
Navajo	148,530	21,788	0.33	96.24
Yiddish	213,064	17,474	0.26	96.50
Hungarian	147,902	13,827	0.21	96.71
Ukrainian	96,568	13,104	0.20	96.90
Gujarathi	102,418	12,057	0.18	97.08
Rumanian	65,265	11,381	0.17	97.25
Formosan	46,044	9,691	0.15	97.40
Serbo-Croatian	70,964	9,512	0.14	97.54
Ilocano	41,131	8,164	0.12	97.66
Panjabi	50,005	7,720	0.12	97.78
Hebrew	144,292	7,167	0.11	97.89
Dutch	142,684	5,860	0.09	97.97
Slovak	80,388	5,755	0.09	98.06
Czech	92,485	5,714	0.09	98.15
Turkish	41,876	5,677	0.09	98.23
Syriac	35,146	5,404	0.08	98.31
Lithuanian	55,781	5,076	0.08	98.39
Other	1,294,837	107,529	1.61	100.00
Total	**31,844,979**	**6,672,201**	**100.00**	–

Notes: The second column (NELP) shows the number of people in the first column who do not have English language proficiency. Figures in the third column represent the proportion of all NELP (i.e., total U.S. NELP population) in each language category.

Source: Data from the 1990 Census as compiled by Stevens, 2000.

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represent linguistic categories that included more than 1 million speakers, and no language except Spanish was spoken by more than 1 percent of the total U.S. population. The Bureau has generated a detailed demographic breakdown of the 50 non-English languages or language families, such as Chinese and Tagalog, most frequently spoken by U.S. residents (U.S. Census Bureau, 1999).

Levels of English Proficiency

Levels of English proficiency differ sharply among subpopulations that speak different languages because these groups differ by age, nativity, duration of residence in the United States, and level of education. The Spanish-speaking subpopulation contains the largest proportion of persons who are not proficient in English; in 1990, approximately 4.5 million (more than 25 percent) of the country's 17 million Spanish-speakers either did not speak English "very well" or did not speak it at all. Other subpopulations with significant proportions of individuals with relatively low levels of English proficiency include those speaking Asian languages (e.g., Chinese, Korean, Vietnamese, Thai, Cambodian, and Hmong[5]) as well as speakers of Portuguese, Russian, French Creole and Armenian.

English language ability is related to nativity. Among the population who spoke a language other than English at home in 1990, 70 percent of U.S.-born individuals spoke English "very well," compared with only 41 percent of foreign-born individuals. English proficiency also varies markedly by age. It has been shown that immigrants who arrive in the United States as young children are almost certain to be proficient English speakers when they are adults, although the effects of age at immigration on English proficiency may be tempered by factors such as family background, educational history, and current familial characteristics (Stevens, 1999). In households where a non-English language was spoken in 1990, more than 62 percent of children between the ages of 5 and 17 spoke English "very well," as opposed to 53 percent of persons aged 65 and over.

In the general population, those who do not speak English or speak it poorly often have low levels of education; a small fraction have such low levels of formal education that they may not be functionally literate in their native language. The Census does not collect data on levels of literacy, a significant omission since many surveys depend on the use of

[5] The case of the Hmong illustrates the variety of paths that language-minority groups may take to the United States, as well as the diversity of educational/literacy skills among such groups. During the Vietnam conflict, the U.S. Central Intelligence Agency (CIA) forged alliances with many Lao ethnic groups, the most visible of which was with the Hmong (Hannah 1987). After 1975, the Hmong faced severe retaliation and many emigrated to the United States as refugees, settling primarily in California, Minnesota, and Wisconsin (Wain, 1981; Knoll, 1982; Duchon, 1997). In the United States, the Hmong have experienced high rates of unemployment, high levels of welfare use, low rates of literacy, and relatively low levels of fluency in English (see, e.g., Downing, 1986; Portes and Rumbaut, 1990). Many of the problems the Hmong have faced in the United States have been due to low levels of literacy in their own language. Few Hmong have more than a few years of formal schooling in Laos, and many, especially women, received no schooling at all (Duchon, 1997).

a written instrument. Many of those with low English proficiency are poor; more than half of these individuals are in poverty or near poverty. It is important to note that lack of proficiency in English is not necessarily associated with poverty in the United States. For example, among Hmong and Navajo who are proficient in English, large numbers remain poor; on the other hand, very few non-English speakers of Japanese, Tagalog, Hindi, Italian, Portuguese, Greek, or Gujarati are poor.

Language-minority subpopulations characterized by low levels of education and high poverty also tend to display relatively high rates of linguistic isolation, as do subpopulations with relatively high proportions of foreign-born, especially recent immigrants and the elderly. Twenty-six percent of elderly who speak a non-English language at home are linguistically isolated. After Spanish, the language groups with the highest proportions of linguistically isolated households include Chinese, Vietnamese, Korean, Cambodian, Thai, and Hmong. Many of these economically disadvantaged language-minority households contain no one over the age of 14 who speaks English fluently. This is problematic for surveys since there is no one in the household who can act as a translator or proxy. The language-minority subpopulations who are poor, relatively uneducated, linguistically isolated, elderly and have low levels of English proficiency may be precisely the groups that are likely to derive the greatest social benefits from having their characteristics and requirements fully documented through national-scale surveys.

Geographic Distribution of Language-Minority Populations

The five most populous states—California, New York, Texas, Florida, and Pennsylvania—contain about 60 percent of the language-minority population, but less than 40 percent of the total U.S. population. Within these states, the language-minority population tends to be concentrated in major urban centers.

Despite the relatively high concentration of language-minority speakers on the coasts and in the Southwest, there are distinct differences in geographic distribution among ethnic subpopulations. Hispanics are concentrated in a few states, tend to be urbanized, and tend to represent a sizable proportion of the population in the areas where they reside. This makes them relatively easy to capture in a nationally representative survey, as they will fall into a normal sampling frame. This also helps to explain recent successes in efforts to improve the representation of Spanish-speaking groups in national surveys. Unlike Hispanics, Asians tend to be more thinly dispersed throughout the country, typically representing 2 percent or less of the population of most states. The main exceptions are Hawaii and California, where Asians who speak non-English languages constitute 23 percent and 10 percent of the total state populations, respectively. It is extremely difficult to obtain nation-wide representative samples of small populations characterized by such geographic dispersion. While oversampling high-concentration strata through multi-staged stratified area sampling designs to enhance minority representation in national-level surveys is effective and cost-efficient for groups that tend to cluster (e.g., African Americans and Hispanics), such sampling designs are less effective when applied to small populations that are geographically dispersed (Santos, 1996; OMH, 1999).

Challenges for Including Language-Minority Populations in Surveys

People who cannot communicate in English are routinely underrepresented in national surveys. Actual rates of non-coverage due to language barriers remain uncertain because 1) survey organizations do not routinely collect information on the number of individuals excluded from the sample because of language difficulties and 2) relatively rare populations are difficult to systematically include within sampling frames that are designed to obtain a national picture. However, failing to develop methods to measure the characteristics of language-minority subpopulations will progressively compromise the scientific quality of data collected through such surveys as the size (and possibly the national proportion) of these groups grows. It is, therefore, good science to figure out how to increase the coverage of these difficult-to-reach subpopulations in national surveys based on a coherent body of scholarship.

If language-minority populations are excluded from surveys, they may end up being excluded from receiving government services they need. In an age of limited resources, policymakers often use data from surveys to assign priorities for funding programs and activities (OMH, 1999). Policymakers may therefore overlook the needs of language-minority populations, not for lack of interest, but because they lack the data they need to recognize the level and extent of unmet needs in these populations.

The specific design features of any social survey are primarily determined by the questions researchers seek to answer. These questions often involve specific populations and the larger policy context that helps to define the objectives of the agency or agencies that have commissioned the research. The survey design includes the definition of survey variables, instrument formulation, methodologies governing data collection in the field, subsequent data processing and analysis, and a sampling plan that will select respondents who can provide data that accurately reflect the characteristics of the targeted population. Practical considerations also shape every survey design. In particular, the characteristics of the target population affect which field methodologies are used—for example, translated instruments and proxies or bilingual interviewers (or both)—as well as sampling techniques. The problems encountered in working out the details of field procedures influence and sometimes change survey objectives (Kish, 1965b).

Difficulties in Assessing Language Usage

Cost constraints dictate that most surveys rely on respondents' self-assessments of linguistic proficiency. The objective validity of such self-evaluation is open to question, and evaluative categories are usually not explicitly defined. For example, respondents can interpret the categories of English proficiency as seen on the Census questionnaire ("very well," "well," "not well," and "not at all") differently since self-reported assessments of proficiency are by nature subjective.

It is difficult to precisely identify and classify the languages that survey respondents speak. With any language, dialects vary and usage changes, and these changes often are highly localized. For example, French would appear to be an unambiguous language category, especially because of the high degree of standardization that has been imposed on Parisian

French over the course of several centuries. Yet, in the United States, French includes the Cajun dialect spoken by native-born individuals, most of whom reside in Louisiana, an array of Creoles spoken by immigrants from several Caribbean countries, and the dialects spoken by immigrants from Francophone Africa and from Canada. Thus, the French-speaking subpopulation, which constitutes approximately 3 percent of the language-minority population and about 6 percent of the elderly language-minority population, is actually splintered into numerous subgroups whose distinctive non-language as well as linguistic characteristics complicate researchers' attempts to compile fully representative data. The same heterogeneity, differing only in degree, is observable in every other language-minority subpopulation. Thus, our data on language-minority subpopulations do not reflect the actual complexity faced by researchers attempting to design surveys that include these groups.

Nonetheless, data gathered from the Census, presently the best available source of information on the linguistic demography of the United States, give researchers an estimate of the nature and overall scale of the practical problems they can anticipate as they plan to include language-minority subpopulations in large-scale surveys of the general population. Furthermore, an array of valid, well-tested probability-based sampling techniques has been developed over the past thirty years and successfully used to gather data on other minority populations; these techniques may be creatively utilized to gather data describing small subpopulations defined by language characteristics (Santos, 1996).

The Multiplicity of Languages

The diversity of languages among non-English speakers makes it difficult to include the language-minority population in surveys and national studies. Data from the 1990 Census suggest that reaching 80 percent of the 6.7 million persons aged 5 and above who did not speak English or who did not speak English well would require including Spanish, Chinese, Korean, French and Italian. Reaching 90 percent coverage would require the use of seven additional languages: Vietnamese, German, Polish, Portuguese, Japanese, Russian, and Tagalog (Table 1).[6] Most data-gathering organizations cannot afford to include 90 percent of the language-minority population because of the extremely expensive processes of translating instruments and hiring/training bilingual interviewers.

Relatively low coverage rates for at least some language-minority populations are inevitable in any national survey effort because it is virtually impossible to overcome all language barriers. Even the Census Bureau, with a budget exceeding four billion dollars for the 2000 Census, limited costs by translating the questionnaire into only five languages: Spanish, Chinese, Korean, Vietnamese, and Tagalog. The Bureau did, however, make other efforts to reach small language-minority populations (see Appendix A). Reducing non-coverage to scientifically acceptable levels can only be accomplished by carefully coordinating decisions about instrument translation and the use of bilingual interviewers

[6] To reach 80 percent of the elderly population who did not speak English well or at all would require the use of nine languages (Spanish, Chinese, Italian, French, Korean, Russian, Polish, Tagalog, and Portuguese). Reaching 90 percent would require the use of eight additional languages: German, Japanese, Vietnamese, Ilocano, Armenian, Greek, Hindi, Yiddish (special tabulation by J. McNally of the Census 1/1000 PUMS).

with information about the characteristics of targeted segments of the language-minority population. Less expensive, but also less satisfactory, methods such as the judicious use of proxies or other household members who speak English and can act as translators may also be exploited when language barriers cannot be otherwise overcome.

The highly diverse array of languages spoken by language-minority subpopulations, and their relative distributions through different strata of the overall population, result from the interaction of many factors: the presence of indigenous language-minority groups; the continued use of non-English languages learned during childhood among both foreign- and native-born; intergenerational transfer and maintenance of language, primarily among first- and second-generation immigrants; and immigration. Clustering of non-English speaking residents in small enclaves may make it unnecessary for some language-minority individuals to ever learn English. The changes in patterns of immigration over the past century are the single most important factor shaping the differential patterns of language distribution apparent in today's language-minority population.

Additional Factors Contributing to Underrepresentation in National Studies

The acquisition of accurate, reliable data from members of small subpopulations is unusually difficult and costly for two other reasons: they often are not geographically concentrated, and elaborate screening processes are required in order to obtain samples large enough to yield statistically valid data. The National Center for Health Statistics (NCHS) has reported that in order to achieve an analytically meaningful oversample of Asians and Pacific Islanders (who constitute approximately 3 percent of the total U.S. population) in the National Health Interview Survey, an additional 15,000 screenings would have to be performed to identify 2,580 eligible households. To achieve the same numerical oversampling of American Indians (0.8 percent of the total population), an additional 158,000 screenings would be required. Cost estimates for attempting such oversamples begin at a minimum of 1.5 million dollars annually (NCHS, 1999). According to 1990 Census figures, no language-minority subpopulation except Spanish speakers exceeds 1 percent of the general population. Conducting general screenings for even a highly limited number of non-Spanish-speaking language-minority subpopulations would be extremely expensive. In addition, computational costs rise when the number of stratifying subcategories used for data analysis increases, as is the case when multiple language groups are identified as analytically significant.

Sampling, Measuring and Interviewing Language-Minority Populations

Sampling Procedures

There are a number of cost-effective sampling techniques that can be used to yield valid, accurate data on language-minority subpopulations (Kish, 1965a; Santos, 1996). One simple method is to use pre-existing special lists to establish a selection frame for the targeted population. Researchers must carefully evaluate the coverage properties of such lists in order to avoid introducing bias. While most lists generated by commercial enterprises cannot be used to produce unbiased samples, some pre-existing lists compiled by government agencies have excellent coverage properties. For example, school rosters provide excellent

coverage of school-aged children on the local level; the records of the Immigration and Naturalization Service provide complete listings of legal immigrants; the Centers for Medicare and Medicaid Services (formerly Health Care Financing Administration) has formulated a list of Medicare beneficiaries that includes more than 95 percent of all U.S. residents aged 65 and above. Using telephone interviews to conduct preliminary screenings can also help contain costs. However, surveys targeting minority populations must supplement telephone screenings with face-to-face screening (a dual-frame technique) in order to attain adequate coverage, because telephone ownership is less pervasive among poor and minority households than in the general population as a whole.

Cumulation is another technique for developing frames that takes advantage of already-accomplished research, and is one of the least expensive methods by which an extensive list of individuals belonging to small subpopulations can be compiled quickly. Researchers identify a relatively large pool of potential respondents by reviewing data gathered over the course of several years through previously conducted large-scale surveys such as the General Social Survey (GSS), which began in 1977. While national surveys like the GSS usually employ probability-based, multi-stage area household sampling strategies that result in the inclusion of only a few respondents belonging to small sub-populations during any single episode, researchers can combine data from several sequential surveys to generate a fairly large number of potential respondents. Cumulation may have significant drawbacks, however. The information derived may be outdated, lists drawn from data gathered over the course of several years may not adequately reflect recent trends such as changes in immigration patterns, and incomplete coding of respondents' language characteristics can preclude identification of language-minority speakers.

Perhaps the most flexible method for increasing the representation of small subpopulations in national surveys is the use of supplementary sampling techniques. Two basic strategies can be pursued: supplements may be integrated directly into national-scale surveys; or independent surveys can be carried out on the subnational level concurrently with national studies. A more sophisticated strategy for integrating supplementary samples into national-level surveys involves the use of multi-stage stratification techniques (Santos, 1991; 1996). First-stage units of a general population sampling frame are supplemented with minority-based Primary Sampling Units (PSUs) from which Secondary Sampling Units (SSUs) are derived through stratification by differential levels of minority concentration. SSUs in strata characterized by higher minority concentrations are then oversampled. This form of supplementary sampling has been a very efficient means of increasing coverage of small populations that cluster in specific areas. The NCHS has used supplementary sampling to target small subpopulations to create the Defined-Population Health and Nutrition Examination Survey (DP-HANES), which is conducted simultaneously with NHANES. The first supplement targeted Hispanic subpopulations (H-HANES) and proved extremely successful in yielding heretofore unobtainable data.

However, conducting supplementary regional or state-based surveys is expensive; in effect, two separate surveys must be financed and fielded simultaneously. Over the long term,

however, the strategy can be economical if the basic design can be applied to a large number of small subpopulations on a rotating basis over the course of several years. For example, the first year's supplementary survey might focus on Spanish-speaking subpopulations; the succeeding year's on Chinese speakers; the third year's on groups speaking French Creole (of which there are several), with a return after a specified interval to the initially targeted subpopulation. In the case of language-minority subpopulations, rotating supplements of language-minority participants may provide data on the complexity of language-minority subpopulations that may not be possible with any other sampling methodology. Data gathered from a number of small-scale surveys carried out on the regional or state level can also be aggregated in order to build a national picture.

The qualitative information on small populations from local supplementary surveys may justify their cost. Compared with the Federal government and large national survey contractors, local data-gathering organizations (sometimes called "boutique" firms) may have better access to and knowledge of the special subpopulations located in their own territory. Such firms have often forged long-standing partnerships with local organizations that act as the "gate-keepers" of their communities; the imprimatur of these trusted neighborhood organizations often increases individual respondents' willingness to participate in social research initiatives. When the targeted population is defined by language, boutique firms typically know the local vernacular, which helps increase communication, trust, and cooperation between researchers, community leaders, and potential respondents.

Survey Instrument Issues

To collect data on language-minority populations, there are a limited number of options available to researchers. They can translate existing research instruments and ancillary documents (e.g., advance letters explaining the purpose of the research), or create new instruments in the languages of the groups to be included. There are clearly advantages and disadvantages to both approaches. Literal verbatim translations are often inadequate, and should be back-translated (i.e., from the second language back into English) to verify linguistic accuracy, although translation efforts should not stop there. Both versions must ask the same or equivalent questions and thereby gather equivalent data. Cognitive equivalence of the concepts being investigated is crucial; the research team should consider consulting with anthropologists, linguists, psychologists, ethnographers, historians, and experts in religion.

If cultural differences are not taken into account when survey instruments are translated, comparisons across subpopulations from different cultures may be seriously compromised (see Johnson et al., 1996). For example, a recent New Zealand study casts doubt on the cross-cultural validity of the European-designed SF-36, an international survey instrument measuring perceptions of health-related quality of life. This study compared responses of New Zealanders of European descent, Maori who had assimilated into European culture, and Pacific Islanders who had not assimilated (Scott et al., 2000). The researchers found that the first two groups gave comparable responses to items in the questionnaire, presumably because they shared certain basic European cultural assumptions

about the relationship between mental and physical health. The responses given by Pacific Islanders, however, were not comparable to those of the other groups because their assumptions about the mind-body relationship differed radically. A similar difference was found between Asian Indian and Pacific Islander elderly in Fiji regarding Western interpretations of health (Panapasa and McNally, 1997).

The cultural differences that researchers must take into account involve not only varying concepts of health, well-being, and the nature of the self, but also differing perceptions regarding hierarchical relationships such as kinship or communal structures. For example, in a recent survey of responses to an antismoking campaign, Mexican-American men found appeals to family responsibility more compelling than arguments based on the importance of preserving one's own health. Some concepts that are commonplace in the U.S. context cannot be expressed in other languages. For example, it may be impossible to collect information on home equity loans from Sudanese Dinka tribe members since this concept does not exist in their culture. Some specific terms that are easily understood or recognized in English may not have an equivalent term in another language. For example, a group of elderly Koreans, long-term U.S. residents with relatively low levels of English proficiency, revealed during health-survey interviews that while they knew the English word "cholesterol," they were unfamiliar with the equivalent Korean term (Hendershot et al., 1996).

Interviewer Expertise

No matter how well survey instruments are designed, there almost always remains the need for bilingual or multilingual interviewers. Linguistic fluency in a language alone is not enough to ensure competent data collection; the educational levels, language abilities, values and beliefs of potential respondents must also be considered. Interviewers must be sensitive to cultural differences both among and within language-minority subpopulations, and should have sufficient linguistic skills to tailor their own language appropriately. This level of linguistic proficiency and adaptability is most often found in native speakers.

The relationship between the interviewer and the respondent can affect the quality of the data collected. Successful interviewers develop an atmosphere of trust and mutual support. Lack of a common culture or of cultural understanding and a common world-view can hinder the development of a fruitful relationship.

One alternative to using bilingual interviewers is using third-party interpreters. This allows researchers to collect information from non-English speakers when no better alternatives are available, but there are several problems with this practice. Use of a third-party interpreter hinders the development of the interviewer-respondent relationship. The presence of third-party interpreters may constrain respondents from responding candidly, especially when sensitive topics are addressed. Third-party interpreters may interpose their own judgments and point of view, in either framing the question or translating the response. Also, the use of untrained third-party interpreters increases the risk of violating respondents' confidentiality. Hence it is essential that third-party interpreters be trained about the importance of respondents' right to privacy and the confidentiality of the information provided.

Problems of Within-Group Heterogeneity

In both translating and creating equivalent research instruments and in selecting and training interviewers, researchers must consider the heterogeneity within language groups. Language-minority subpopulations differ linguistically, demographically, and culturally. In all languages, accepted forms of usage are evolving constantly, and such changes are often highly localized. The Korean or Russian spoken by individuals who immigrated 25 years ago, for example, differs from that of more recent immigrants, who may perceive long-term migrants as speaking an archaic form of their native language. Both groups' language will be affected by their exposure to English, but the length of time they have been interacting within a smaller community of speakers of that language will result in different dialects or patterns of speech.

Colloquialisms used by younger members of language-minority subpopulations are usually highly localized and often represent appropriations of English-language slang; these expressions may only be understood within the specific community, often an inner-city neighborhood. Bilingual interviewers must be skilled and flexible enough to detect and accommodate these highly particularized linguistic patterns.

Perceptions of social appropriateness differ widely among ethnic groups and may affect responses to surveys. What is considered polite or acceptable by one subpopulation may be viewed as offensive, alienating, or inappropriate by another. A follow-up to a survey of elderly non-English-speaking Koreans residing in the United States who had participated in ACASI (Audio Computer Assisted Self Interview) interviews revealed that the respondents thought the female voice used in the computerized recording sounded too young. While the survey designers had carefully chosen this voice to be as pleasing as possible, the respondent reaction was affected by the respect their culture accords the elderly (Hendershot et al., 1996). Linguistic usage and cultural attitudes of various language-minority subpopulations may vary not only according to age and educational level, but also by class, regional origin, and ethnicity. Standard, grammatically correct usage, an academic vocabulary, and even a particular regional dialect can significantly hinder communication with subpopulations characterized by relatively low levels of education or who identify strongly with their region of origin, class, or ethnic group. Bilingual interviewers who lack professional training or do not possess sufficient linguistic flexibility may unwittingly activate stratification structures if their accents, dialectal patterns, or behaviors betray regional or class origins and attitudes different from those of respondents; potential respondents may develop a sense of alienation or distrust.

These regional dialect and class issues are community-specific and cannot be predicted without local information. This highlights the importance of establishing partnerships with local community associations, such as advocacy groups, charitable and religious organizations, civic groups, school boards, and local government task forces. Members of such organizations are often willing to help design research, review translated materials for accuracy and cultural appropriateness, and assist in developing strategies for locating and establishing rapport with potential respondents. Such input from local community leaders is invaluable as a sign of endorsement, lending legitimacy to the research effort, and can be crucial to the success of

data-collection efforts. These organizations can also provide a means of sharing research findings with the community upon completion of the study (Mays, 1999).

Strategies for Exerting Quality Control Over Translation and Interview Practices

In light of the numerous linguistic and cultural variables that affect data collection, rigorous quality control over translation and interview practices is crucial to achieve cultural appropriateness, accuracy, and sufficient precision, thereby ensuring the scientific integrity of the information gathered. Standardized protocols for translating survey instruments and for bilingual interviewing do not exist. Instrument translation and subsequent cognitive testing, as well as the recruitment and training of bilingual interviewers, often receive limited attention in most major social research initiatives, usually due to time and money constraints.

In the United States, survey instruments and related documents are almost always developed in English first, even when translation into at least one other language (most often Spanish) is planned. Once the translation is completed, back-translation is often used as a verification process. Cognitive testing for equivalence is time-consuming and therefore often not done. While back-translation can provide confirmation of the literal accuracy of a translation, it is inadequate for evaluating cognitive equivalence or cultural appropriateness (personal communication, Kelly Jones Dresden, July 2000).

Some smaller data-gathering organizations have begun experimenting with concurrent instrument development in English and a second language. To ensure that the data gathered in the two languages are comparable, these simultaneously developed instruments are rigorously tested for cognitive equivalency, often using monolingual focus groups in each language. This dual-focus approach is appealing because it avoids the problem of timing. Frequently, data collection in English must be initiated while the instrument is being translated into the second language. This practice precludes changes to the original instrument in order to achieve cognitive equivalence, or makes such changes more costly.

Because of the semantic precision required in developing cognitively equivalent instruments, it is important to use professionally trained translators who understand the purpose of the research project and the meaning of the instrument items. Similarly, the recruitment and training of bilingual interviewers is an important consideration. To ensure that interviewers possess adequate fluency in the target language(s) and the ability to employ various levels of usage to accommodate the linguistic characteristics of potential respondents, native speakers or persons with native-like proficiency should be used. Interviewers' linguistic competency should be objectively demonstrated, e.g., through standardized assessment of reading, conversational fluency, and listening comprehension. The quality of an interviewer's voice can also be assessed objectively: professionally trained, pleasing voices characterized by a relatively neutral accent are generally most effective. However, as noted earlier, what constitutes a "pleasing" voice can be largely culturally determined. Hiring interviewers from the communities in which targeted respondents reside can minimize cultural communication barriers; however, their use can also evoke deeply held culturally determined beliefs or customs and raise issues about confidentiality of responses that may influence the respondents' willingness to provide certain types of information, such as details of personal health or intimate relationships.

Because of the complexity of the relationship between interviewer and respondent, training interviewers will always be a challenging part of data collection. Similarly, instrument translation is unlikely to ever be entirely free of ambiguities or to be perfectly culturally appropriate. Tensions exist between the need for literal accuracy and the need for semantic/cognitive equivalence or comparability. The implicit contradiction between these goals is especially apparent in translations of precisely worded survey instruments that are required to meet the highest standards of scientific accuracy.

Technological Innovation and Linguistic Logistics

The technological aids available for interviewing represent a series of remarkable advances over what was available 25 years ago: laptops, cell phones, Computer Assisted Telephone Interviewing (CATI), Computer Assisted Personal Interviewing (CAPI), and Audio Computer Assisted Self Interviews (ACASI), which obviate the need for literacy. The Internet has the potential to add even greater flexibility for enhanced communications to support interviewing, and should reduce associated travel costs.

These, however, are primarily communications media. Since the early 1990s, a new generation of technology has emerged for translation. This technology has been developed largely through Department of Defense initiatives, based on needs for linguistic training and translation/interpreting services for multiple purposes. While a new level of sophistication exists in these technologies, there are limitations to their widespread use in national surveys and research studies. Nonetheless, they show promise for increased efficiency and lower costs as they are developed. The relative scarcity of professional bilingual translators and interviewers who also understand survey methodology increases the urgency and importance of developing such technologies, and argues strongly for the consideration of ways to combine methods. For example, the use of machine technology as a first "rough cut" for translation can reduce the amount of time required for professional translators, allowing them to refine and correct rather than carrying the entire translation burden. Beginning with an existing instrument in the target language and having a professional translator with an in-depth cultural understanding of the target population modify that instrument to make it culturally appropriate can also save time, effort and money, although clearly the appropriateness of the instrument for the specific purpose of the study must also be carefully evaluated.

Innovations that have emerged in the area of machine translation have been driven by markets both inside and outside the United States. The focus has been on languages needed to reach large groups of speakers, such as Spanish, French and Chinese. There clearly is less commercial demand for translation to what can be called "minority languages," that is, those with fewer speakers. In addition, technological translation tools require significant maintenance to be worthwhile. For these reasons, machine translation is not a quick and easy answer to the challenge of including language-minorities in national surveys and studies. However, there are applications in current use and others in development that may be helpful.

The goals of any machine translation program are to be of general purpose (able to translate any text), of high quality (matching human translation), and fully automatic

(requiring no user intervention). Existing machine translation applications can meet any two of these goals but not all three at once. There are three major types of machine translation applications currently in use: knowledge-based, corpus- or example-based, and "human-in-the-loop" or efficiency tools. Each offers advantages and disadvantages. Knowledge-based systems use detailed knowledge of the language (grammar and other rules) to create high quality translations, but require an extensive development effort. It takes at least a year to develop such a system for a new language pair. Corpus-based machine translation systems translate by matching text in large databases of parallel text (similar to a technique called "translation memory"). More generalized example-based systems tag words in parallel text, and then translate sentences and phrases that have never been seen before based on matching words and phrases with common tags. Human-in-the-loop tools, as exemplified below, typically are used in conjunction with knowledge-based and/or corpus-based systems to enhance efficiency.

Corpus-based systems are especially useful for dissemination purposes; they have one source language, are restricted to a controlled style, and address a single topic or domain. Because corpus-based systems are so tightly controlled and developed for special purposes, they offer a full semantic analysis. For some basic communication purposes, lower quality translations may perform adequately, but have real-time requirements. They can, however, be developed as soon as a parallel corpus of examples is available.

There are some examples of machine translation applications in use or being piloted that have been developed for the Department of Defense. One, DIPLOMAT, is a rapid-deployment, wearable, speech-to-speech translation device that was developed for English and Croatian, Haitian Creole, Spanish, and partially developed for Korean. DIPLOMAT combines corpus-based and knowledge-based approaches, plus a morphological analyzer and a user-interface. The combination of methods or machine translation "engines" allows developers to combine strengths and avoid weaknesses of the individual approaches, and uses a statistical language modeler to select the best combination of outputs. Using multi-engine machine translation, an application for a new language can be developed within weeks; however, the new application undergoes improvement for months or years.

TONGUES and NICE are other examples of the use of these combined approaches. TONGUES is an audio-voice translation guide, a hand-held speech-to-speech system. The example-based system combines a word-for-word dictionary translation, a glossary database for phrasal translation, and both general and domain-specific databases of sentences. It is being developed initially for humanitarian aid and applications other than war (e.g., dealing with civilian leaders), and the prototype is currently being pilot tested in Croatian and English by U.S. Army chaplains. Translations produced by a system such as TONGUES are generally of lower quality than those produced by extensive knowledge-based system, but can be developed more quickly. Examples of domain-specific sentences, phrases, and words are collected to form the corpus that serves as training data for speech recognition and speech synthesis for this system. Because it is intended for domain-specific conversation, TONGUES assumes that the interviewer and respondent are face to face, and the system uses human feedback to clarify meanings. While it would not be appropriate

for telephone survey administration, TONGUES could be useful in door-to-door interview administration for some surveys and research studies. Some potential disadvantages in survey use are that it may feel unnatural to respondents, there is a small delay for processing time, and general purpose speech recognition suffers from low audio quality such as that through a telephone. While TONGUES would still require human translators to produce the corpus specific to the project (i.e., to translate the survey), it could significantly speed the translation of survey materials.

NICE, or Native-language Interpretation and Communication Environment, uses multi-engine machine translation to enable speakers of electronically underrepresented languages to participate in the information age. Through NICE, it is hoped that policy makers will be able to access ideas, viewpoints, and information from developing nations. In addition, it can provide assistance for unforeseen translation needs, such as humanitarian aid requirements, and can be used in the documentation and preservation of endangered languages. Part of a larger program of Western Hemisphere collaboration, NICE currently includes Spanish and two indigenous languages of Latin America. While still under development, NICE offers promise for use in languages with smaller numbers of speakers where professional bilingual translators and interpreters are difficult to find.

Translingual Information Detection, Extraction, Summarization (TIDES) is being developed for the Department of Defense in response to the demand for an "electronic linguist." It is designed to support monolingual information analysts by automatically processing more than a billion information sources daily, including text, audio and web-based information in various languages. There are not enough linguists available to manage the huge volume of information, especially in minority languages. This application is intended to enhance international operations and increase the military's ability to respond rapidly to crises, including humanitarian assistance, disaster relief, and consequence management.

Summary

The increasing number of individuals in the United States who do not speak English well represents a major challenge for health and social service agencies, educators, policy planners, and the social science research community. Although only about three percent of the U.S. population aged 5 and over speak English poorly or not at all, the proportion is substantially larger for specific population subgroups. Demographers and other social scientists usually use large-scale household surveys, based on probability sampling, to collect data that accurately represent the characteristics of the U.S. population as a whole. Most surveys limit their interviewing to English or English and Spanish, and respondents must have a relatively high level of proficiency in that language. If the proportion of language-minority individuals in the population increases, the representativeness of national samples is increasingly compromised. Excluding non-English speakers omits many of the most vulnerable in our population. Including respondents who do not speak English, or who have low levels of English proficiency, is costly due to the need for extensive screening procedures, instrument translation, and the use of fully trained, culturally competent bilingual interviewers.

Important scientific knowledge can be gained from better representation of language-minority subpopulations, which will prove crucial to the Presidentially mandated initiatives aimed at eliminating health disparities in minority populations as part of Healthy People 2010, currently being pursued by the DHHS and the National Institutes of Health (NIH). Inclusion of language-minority speakers in large-scale statistical studies of the U.S. population is a natural complement of trans-NIH efforts to encourage the greater participation of members of minority groups in clinical trials and other aspects of medical research.

A panel of experts pointed out that the challenges of including language-minority populations in national surveys and studies are not new and that many resources are already at hand. In addition, there are many new technologies and potential solutions on the horizon. However, in view of strong national commitments to (1) improving the inclusion of minorities in clinical trials; (2) reducing health disparities among subpopulations; and (3) developing cultural competence in health service delivery,[7] researchers and policy makers should give added attention to language as a potential barrier for inclusion in national surveys, as well as for access to health care and social services.

Barriers to Inclusion

A recurring theme throughout the workshop and this report is that **cost is the most significant barrier to the inclusion of language-minority populations in national studies**. But researchers and policy makers must also consider the costs—in terms of data validity and sample bias—of ***not*** including these subpopulations. Those omitted constitute, in many instances, not simply a parallel group that differs linguistically and culturally. Rather, the excluded often represent segments of the U.S. population that are less educated, of lower socioeconomic status, and more vulnerable along a number of social and health dimensions, and for all these reasons in greatest need of services whose provision may be based on the data collection in question.

Four necessary, but expensive, tasks were identified: (1) sampling to get sufficient numbers of subjects who do not speak English well; (2) translating or developing survey instruments (including the concomitant costs of vetting the translation, conducting focus groups, and/or piloting surveys); (3) recruiting, hiring, and training bilingual interviewers, and (4) contacting and interviewing subjects who live in rural or geographically diverse locations. And given the time-consuming nature of tasks of (2) and (3), **time itself also becomes a barrier.**

The geographic distribution of minority language populations may be a significant barrier. Language-minority individuals are often difficult to include in studies either because they are clustered in small, possibly remote areas, or because they are not concentrated in any particular area. Cost-effective sampling strategies based on geographic location therefore often cannot be used.

Language change over time is a barrier to inclusion of language-minority groups in research. All languages change over time; the version of language spoken by recent immigrants is likely to differ significantly from that of individuals who immigrated several years

[7] For a definition of cultural competence, see the Office of Minority Health website http://www.omhrc.gov

ago. Groups living in relatively isolated communities with little contact with their country of origin are likely to have developed different dialects from those in more urban areas, even if both groups immigrated at the same time.

Lack of coherence with other research goals presents a barrier. The issue of addressing specific language groups may not be well-integrated into a project's major research focus, and may therefore seem an ad hoc, add-on component that does not fit well with the overall research goals and design.

Use of community members as translator/interpreters may be a barrier. While the use of local translators and interpreters can sometimes improve the quality of survey data, their use also can be a barrier with regard to issues of confidentiality and/or culturally sensitive topics that respondents are uncomfortable with or reluctant to openly discuss with someone from their own community. Similarly, someone from the local community (either the current community or the community of origin of an immigrant) may invoke the class structure of the culture of origin, which can interfere with the goals of the research.

Enabling Inclusion

In spite of the barriers mentioned above, it is important to find ways to allow surveys and research studies to capture the increasing linguistic diversity of the United States and hence be truly nationally representative. While not all studies can achieve this, there are some current practices that offer useful approaches that should be considered.

It is possible to **decrease cost through innovative sampling approaches**, rather than screening the general population. For example, researchers can identify subjects through pre-existing lists based on administrative records (e.g., birth registries, INS records, Medicare records). Other potential savings may ensue from judiciously employing commercially compiled lists, using telephone interviews to conduct preliminary screenings, and cumulating data from repeated surveys in order to increase sample sizes.

Instrument translation should incorporate and expand on several important practices. Translation should be done by professional bilingual translators, and the translations should be vetted (judged as to linguistic and cultural appropriateness) by monolingual speakers of the target language. Translated or parallel instruments should undergo cognitive testing to determine that in fact they test/query the same concepts. Researchers should allow flexibility for inclusion of Anglicized dialects. The retention/inclusion of English terms in the translated instrument is important for cases when a concept may not exist in the target language and culture. Translations should also be tested in focus groups of monolingual speakers from or typical of the target research group, and should be piloted whenever possible.

Researchers should build in time for translations when designing and planning studies. Time should be allowed to complete the English version of an instrument before beginning the translation, and time to translate, evaluate, and test the translated version prior to the initiation of actual data collection in either language. Alternatively, researchers could develop (or contract development of) a parallel, culturally appropriate instrument simultaneously with the English language instrument, or lagged behind the English version but overlapping in timing.

The rapidly expanding sophistication of **machine technology can reduce the amount of time required for professional translators** by allowing them to refine and correct rather than shoulder the entire translation burden. Although not applicable in all cases, some research should benefit from using one or more of the three major types of machine translation currently in use—knowledge-based, corpus-based, and human-in-the-loop.

In order to complement and inform future activities, researchers should ensure that they **make optimal use of existing knowledge by building on the work of others and collaborating across disciplines**. Researchers should:

- Gather and share the experience of international organizations that already have multilingual survey experience (e.g., the United Nations, Organisation for Economic Co-operation and Development, World Bank, Demographic Health Surveys, World Health Organization).
- Archive translations and source texts to share and to combine with those of colleagues for potential use in machine translation memory databases.
- Use existing surveys as a starting point whenever feasible. For example, a survey from another country, already written in the language of that country, might require refinements to accommodate cultural adaptations that have taken place since a group emigrated, but could provide at least a basis to build on.

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Appendix A. Recent and Current-Practice Examples

Although there are no standardized protocols for translation and bilingual interviewing, many national surveys have developed methods to accommodate respondents who speak languages other than English. These methods have been influenced by advances in the growing body of scholarship devoted to the effects of the interviewer/respondent relationship on data quality, to theories of translation, and to issues of cross-cultural validity. There are several examples of practices from which we can learn and on which to base some recommendations for inclusion of language-minority groups in national studies. The first is an historical example, that of refugee surveys performed under contract to the U.S. Government in the 1970s and 1980s. The others are current large-scale national data collection efforts that have grappled with the problems of developing cost-effective, practical, state-of-the-art approaches to formulating linguistically and culturally appropriate methodologies for communicating with language-minority speakers: the decennial census, the New Immigrant Survey (NIS), and the Early Childhood Longitudinal Survey of a Birth Cohort (ECLS-B). For information on the treatment of language-minority populations in other ongoing national surveys, see McNally (2000).

Refugee Surveys in the 1970-80s

After the 1975 influx of Southeast Asian refugees to the United States, the Government undertook periodic national surveys to assess how well the refugees were adapting. In the 1980s the surveys were changed to annual surveys of respondents who had been in the country five years or less. These surveys, which represent 25 years of data with a reasonable measure of consistency over time, yield important lessons on the inclusion of linguistic minorities in survey research. Refugees often represent an influx of a new language minority group, rather than an accretion of a group already present in the country. This means that researchers must face the challenge of finding bilingual or multilingual translators and interpreters. For the early surveys, there was an apparently unresolvable tension among the three goals of the surveys: to adequately represent the people, to standardize the methods and context to allow for comparison across populations and regions and through time, and to understand who these people were, how they were adapting, and why there might be difficulties.

The early refugee surveys demonstrated that national origin was not the same as ethnicity, and that the assumption that there was a "national" language was often erroneous. Hence, national origin was abandoned in favor of a five-group ethnicity model in which ethnicity was coterminous with language: Lao, Hmong, Khmer, Vietnamese and Chinese (limited to Chinese from Viet Nam). Today this five-group approach remains the standard convention, and provides a categorical scheme that is practical and defensible. However, this model does not address two fundamental problems: how to deal with smaller populations and how to deal with class, regional, and religious variations with the larger populations.

The 2000 Census

While not a survey, the United States Census represents the baseline source for the most comprehensive information on non-English speaking individuals in the United States. As part of its mandate, the Census Bureau attempts every 10 years to obtain information on all individuals residing in the United States. They are the only organization that makes a concerted effort to obtain demographic and socioeconomic data regardless of the language employed by the respondent.

Population and Bureau staff characteristics, as well as time and money, weighed heavily in the decision about the number of languages into which the Census questionnaire should be translated. In 2000, households receiving a census form in the mail had the option of requesting a questionnaire in one of six languages: Chinese, English, Korean, Spanish, Tagalog, and Vietnamese. Approximately 2 million questionnaires were requested in these six languages. Preliminary estimates suggest that the response rate for each group ranged from 30-46 percent.

For the 2000 Census, the Bureau initiated a program called the Census 2000 Language Program (Martinez, 1998). This effort was designed to maximize the completion of census information and overcome language barriers that traditionally have limited some individuals/households from participating in the decennial census. Census 2000 Language Assistance guides were available in 43 languages beyond the six mentioned above, and were prepared for both the short and long census forms. The printed guides consisted of translations of the questionnaire, multi-lingual instructions, and visual aids that an individual could use in order to complete the English version of the form. Fifteen million such guides were provided for dissemination.

The Census used both centralized and decentralized data collection methods, including mailings, personal visits and telephone interviews. The Bureau used field representatives with fluency in specific languages, and to accommodate localized linguistic variations, the Bureau hired more than 300,000 bilingual interviewers from local neighborhoods throughout the country. The Bureau also engaged field representatives and regional office staff to identify interpreters from local organizations to serve as interviewers. Even with these efforts, officials estimate that approximately 1 percent of all non-responses during the 2000 Census resulted from insurmountable language barriers.

The Early Childhood Longitudinal Study-Birth Cohort

Language minority families present special challenges for the Early Childhood Longitudinal Study's Birth Cohort (ECLS-B) study. Data collection methods will include CAPI interviews with parents, direct assessments of children, self-administered paper questionnaires for fathers, and CATI interviews with child care providers. About 2,000 Asian, 1,500 Hispanic, and 1,000 American Indian births will be included in a national sample of about 15,000 children born throughout 2001. The ECLS-B approach to language minority issues is to make every reasonable effort to include these families in the study, to collect data without compromising quality in any major way, and to be sensitive to cultural differences presented

by these families. At the same time, researchers are attempting to be mindful of the fixed resources available to the project and make the best tradeoffs they can to reach out to minority language families without jeopardizing the overall study design. They have developed specific criteria and decision rules so that the procedures for including language-minority families are not arbitrary and the data are collected in a standardized manner. The approach is still under development, and is being tested in the field during 2000 and 2001. Spanish speakers are by far the largest language minority group in the U.S. Spanish-speaking field interviewers will collect data from families who prefer to speak Spanish. There are Spanish versions of all data collection instruments and materials. For the most common Asian languages spoken in U.S. households with young children (Mandarin, Japanese, Korean, Vietnamese, Thai, Cambodian, and Hmong), outreach materials and telephone assistance are available. A Chinese version of most of the study instruments has been tested and is currently under review.

Field staff will be recruited from local areas where the sampled families reside. The staff includes interviewers who speak several Asian and Native American languages; however, the cost of supporting travel for staff throughout the country to match all the sampled households that prefer to speak those languages in the interview would be prohibitive. Data will be collected from those households primarily with the aid of interpreters. Moreover, some assistance will be provided by central office telephone interviewers who speak these languages. Most of the ECLS-B direct child assessment measures are not very sensitive to language at the 9-month data collection point. For the 18-month data collection round, a version of the Massey attachment sort that has been translated into Spanish, Chinese, and Japanese is being tested. In both of these first two rounds of data collection, teaching interactions between parent and child will be videotaped. Spanish-speaking coders in the central office will code tapes from Hispanic households; other languages spoken on the tapes will be translated into English and transcribed for coding. Although much of the focus in developing the ECLS-B language minority protocol has been on the first two data collection points, their general approach incorporates a longitudinal perspective from which they address issues that are likely to occur over the course of the 6 waves of data collection, ending when the children are in first grade.

The New Immigrant Survey

The goal of this study is to advance the understanding of the characteristics of immigrants and their children, and the process of immigration and its impact on the United States. Past immigration research faced several serious challenges because of data limitations: most data on immigrants are cross-sectional, so dynamic processes related to individual immigrants cannot be investigated; sample sizes are usually extremely small, so analysis of individual country-of-origin groups is not possible; data on legal status (legal versus unauthorized) and visa category (e.g., refugee versus employment versus family reunification) are unavailable; data on entry cohort and length of time since entry are often misleading; and immigrants who return to their home country are systematically excluded.

Building on 20 years of input from expert panels, researchers are fielding the New Immigrant Survey, which avoids these problems. The sample, based on administrative records from the U.S. Immigration and Naturalization Service, is representative of new legal immigrants. The survey is longitudinal, collects retrospective data, includes information on immigrants themselves, their children (both U.S.- and foreign-born) and other household members, and follows immigrants who leave the United States.

The pilot for this study (NIS-P) developed new research strategies for drawing the sample, locating sampled immigrants, subject retention, interview languages, sensitive questions, and cost-effective procedures. The NIS-P was a telephone survey based on a representative sample of persons admitted to legal permanent residence (that is, of people granted a "green card") during July and August 1996 (Jasso et al., 2000). Interview instruments were translated into six languages: Spanish, Chinese, Russian, Polish, Korean, and Vietnamese. Bilingual interviewers conducted interviews in these languages and eleven others. Overall, 44 percent of the interviews were conducted in English, 26 percent in Spanish, and the remaining 30 percent in the sixteen other languages. Item response rates were considered comparable to or better than similar questions on the 1990 U.S. Census. Importantly, the survey provides information on topics that previously could not be addressed due to lack of or unreliable data: immigrants' educational levels, language skills, income, links between legal and illegal immigration, marriage, health, mobility, and religion.

Lessons learned from the NIS-P are that researchers must confront several barriers to inclusion when they are designing and implementing surveys. An example is the geographic dispersion of some population subgroups. In order to ensure appropriate inclusion of all groups, researchers must be willing to incorporate costs and time required to (1) translate and pilot instruments so that they will be culturally appropriate; and (2) train and recruit interviewers. To ensure data quality, researchers must integrate the issue of inclusion of language-minority groups into the design and planning of large surveys and studies, rather than allowing these issues to be dealt with ad-hoc after the design phase. Novel approaches used in the NIS-P included preparation for dealing with multiple languages in advance, offering respondents a choice of their home language or English, using well trained interviewers, using an introductory script, and experimenting with randomly assigned versions of the translated instruments. The investigators felt that their approach maximized data quality, avoided activating stratification structures, and preserved respondents' freedom to grow and change.

Appendix B. Inclusion of Language-Minority Populations in National Studies: Challenges, Opportunities, and Best Practices

AGENDA

July 27–28, 2000

National Institutes of Health
Natcher Conference Center
Building 45, Rooms E1 and E2

Sponsored by
National Institute of Child Health and Human Development
National Institute on Aging and
Office of Research on Minority Health

Thursday, July 27, 2000

2:00 p.m. Greetings and Introduction
Rose Li, Chief, Demography and Population Epidemiology
Behavioral and Social Research Program, NIA

Welcoming Remarks and Introduction of Keynote Speaker
John Ruffin, Director, NIH Office of Research on Minority Health

Keynote Address
Nathan Stinson, Deputy Assistant Secretary for Minority Health
OPHS, DHHS

3:30 p.m. Overview: U.S. Linguistic Demography
Gillian Stevens, Associate Professor, Department of Sociology
University of Illinois at Champaign-Urbana

Overview: How Major U.S. Surveys Handle Non-English-Speakers' Participation
James McNally, Director, NACDA, University of Michigan

4:30 p.m. Discussion

6:00 p.m. No-Host Group Dinner—West End Grill, Bethesda, MD
Speaker: **Thomas Perez**, Civil Rights Office
ASPE, DHHS

Friday, July 28, 2000

8:00 a.m. Coffee and Check-in

8:45 a.m. Greetings and Opening Remarks
Rebecca L. Clark, NICHD

9:00 a.m. Welcoming Address
Yvonne Maddox, Acting Deputy Director, NIH
and Deputy Director, NICHD

9:20 a.m. **Current Practices—What Works in the Field and What Doesn't**
(How and When To Translate, Cultural Considerations, Improving Response Rate, Supply of Bilingual Interviewers, etc.)

Richard Bitzer, Lead Assistant, Division Chief for Surveys, U.S. Census Bureau

Guillermina Jasso, Co-Principal Investigator, New Immigrant Survey
New York University

Brad Edwards, Westat, Project Director, Early Childhood Longitudinal Study-Birth Cohort

Patty Maher, Associate Director, Data Services Division of Surveys and Technologies, University of Michigan Institute for Social Research

Marjorie Hinsdale, Director of the National Household Survey on Drug Abuse
Research Triangle Institute (for SAMHSA)

David Haines, George Mason University

10:20 a.m. Break

10:30 a.m. Discussion

11:00 a.m. **Technological Innovation and Linguistic Logistics**
(e.g., translation tools, artificial intelligence, feasibility issues)

Robert Frederking, Senior Systems Scientist, Language Technologies Institute, Carnegie Mellon University, *"Current Research in Translating Minority Languages"*

Marilyn Gaska, Manager, Advanced Technology, Lockheed Martin Federal Systems
"TONGUES: Automated Translation of Conversation for the U.S. Army"

Kelly Jones Dresen, Director, Translation Department, Comprehensive Language Center, Inc., *"Theory vs. Practice: Translation, Technology, and Minority Languages"*

Noon Discussion

12:30 p.m. Lunch

1:30 p.m. **Barriers, Solutions, and Future Directions**
(e.g., costs, logistics, and cultural considerations; possibilities for cooperation, etc.)

Chair: **Peggy McCardle**, NICHD

Panelists: **Katherine Wallman**, Chief Statistician, Office of Management and Budget
Raynard Kington, Director, National Health and Nutrition Examination Survey, National Center for Health Statistics, CDC
Craig Coelen, President, National Opinion Research Center
Wendy Baldwin, Deputy Director for Extramural Research, NIH

2:30 p.m. Discussion

3:00 p.m. Wrap Up
Robert Santos, Principal Research Associate, Urban Institute

3:30 p.m. Adjournment

4:00 p.m. Debriefing with Panelists

Appendix C. Biographical Sketches of Presenters

Wendy Baldwin, Ph.D. was appointed National Institutes of Health (NIH) Deputy Director for Extramural Research in February 1994. Dr. Baldwin has also served as Deputy Director of the National Institute of Child Health and Human Development (NICHD) at NIH and as the Chief of the Demographic and Behavioral Sciences Branch of NICHD. Dr. Baldwin currently heads a Public Health Service reinvention laboratory for the extramural program at NIH. In addition, she has been involved in the implementation of the NIH Revitalization Act regarding the inclusion of women and minorities in research. Her degrees are in social demography, with special attention to issues related to fertility, infant mortality, family, child well-being, AIDS risk behavior, and research and statistical methods.

Richard Bitzer is Lead Assistant Division Chief for Surveys at the U.S. Census Bureau. Mr. Bitzer has worked as a Survey Statistician for over 29 years at the U.S. Bureau of the Census. He has spent almost all this time in the Field Division. He has had two tours of duty at headquarters in Suitland, MD, and one tour of duty in the New York, Boston, and Philadelphia Regional Offices. He has worked on the 1980 and 1990 Decennial Censuses as well as all the major demographic surveys administered by the U.S. Census Bureau. He has an undergraduate degree in mathematics from Millersville University.

Rebecca L. Clark, Ph.D. is a Program Official with the Demographic and Behavioral Sciences Branch of the National Institute of Child Health and Human Development. She manages a research portfolio in immigration, internal migration and population distribution, race and ethnicity, population and environment, demographic methods, and oversees several of the DBSB Population Centers. Before joining NICHD in February 2000, Dr. Clark was a senior researcher at the Urban Institute, where she conducted research on impacts of immigrants on the United States, Federal expenditures related to children, and other issues related to child well-being. Dr. Clark received her Ph.D. in Sociology (Demography) from Brown University in 1989.

Craig G. Coelen, Ph.D., recently appointed President of the National Opinion Research Center (NORC) at the University of Chicago, has more than 30 years of experience in the management and development of research organizations and a record of extensive research on the financing and delivery of health care services. An economist who earned his doctorate from Syracuse University, Dr. Coelen taught econometrics and macroeconomic theory at Northeastern University, Boston, MA. Dr. Coelen moved into research administration and project direction in 1975 when he joined Abt Associates in Cambridge, MA, where he rose to the position of Senior Vice President and head of the Government Research Division. In 1991, Dr. Coelen became Senior Vice President of the Urban Institute in Washington, DC, where he served for almost 10 years before accepting the presidency of NORC.

Kelly Jones Dresen is the Director of Translation and Interpretation Services for the Comprehensive Language Center in Arlington, VA. She and her staff oversee translation and interpretation projects for the U.S. Government and private industry in more than 100 languages. Recently, Ms. Dresen managed the translation into 49 languages of the Census Bureau's *Language Assistance Guide for Census 2000.* Ms. Dresen has more than 12 years of experience in the translation industry and has witnessed the effects of technological innovation first-hand.

Brad Edwards is a Vice President and Associate Area Director at Westat in Rockville, Maryland. He directs the Early Childhood Longitudinal Study-Birth Cohort (ECLS-B), a major new longitudinal survey for the National Center for Education Statistics (NCES) that will shortly begin enrolling a cohort of 15,000 babies born in 2001 and sampled from birth records. Data will be collected from the children, their parents and child care providers, and (eventually) their schools, using direct child assessment methods combined with computer assisted personal interviewing. Mr. Edwards is Westat's corporate manager for two other longitudinal projects, the Kindergarten component of the ECLS (again, for NCES) and the Medicare Current Beneficiary Survey for the Center for Medicare and Medicaid Services (formerly the Health Care Financing Administration). His current research interests include usability issues in computer-assisted data collection systems, survey incentives, and methods for including language minorities in surveys. He began his survey research career at the National Opinion Research Center, first in Chicago and then New York, and also worked for Response Analysis Corporation in Princeton. He has a B.A. in Geography from the University of Chicago and participated in an Executive M.B.A. program at New York University.

Robert Frederking, Ph.D. is a Senior Systems Scientist at the Language Technologies Institute (LTI) at Carnegie Mellon University and the Chair of LTI's graduate programs. He is currently working on several projects in speech translation (TONGUES, LingWear, Nespole) and cross-language information access (MuchMore). He was the leader of the DIPLOMAT project, which combined CMU's research in rapid-deployment machine translation, speech, and wearable computers to produce a wearable speech-to-speech translator that could be adapted quickly to new languages. Dr. Frederking received his Ph.D. in Computer Science/Artificial Intelligence from Carnegie Mellon University in 1986. He has consulted for Carnegie Group Inc. and held research positions at CMU's Robotics Institute and Siemens Corporate Research Laboratories in Munich, Germany.

Marilyn Gaska, Ph.D. is a senior member of the technical staff and Manager of Advanced Technology at Lockheed Martin Federal Systems in Owego, NY. She is also the Program Manager for Army ACT II BMTS and TONGUES contracts. She has been a technical architect on Department of Defense proposals and programs as well as a Principal Investigator for independent research and development projects involving commercial off-the-shelf open enterprise and e-business architectures for both combat support and commercial systems. She completed her Ph.D. in Systems Science at Binghamton University in May 1999.

David Haines, Ph.D. is an Associate Professor of Anthropology at George Mason University. He is the editor of three books on refugees in the United States including *Refugees as Immigrants* (1989), a compilation of the first decade of survey research on Southeast Asian refugees. More recently, he has co-edited *Illegal Immigration in America* (1999) and *Manifest Destinies: Americanizing Immigrants and Internationalizing Americans* (2000). In addition to immigration issues, Mr. Haines has published work on Vietamese social history, policy and operational aspects of governance, and American culture and society. He was a research and policy analyst with the Federal refugee program, a Fulbright Fellow examining refugee programs in Western Europe, and a senior manager in State government before joining the staff at George Mason University.

Marjorie Hinsdale has been a Survey Director with the Research Triangle Institute (RTI) since 1990. Since 1998, she has served as Director of Instrument Assessment and Development for RTI's largest and most complex survey project, the National Household Survey on Drug Abuse (NHSDA). She specializes in developing data collection instruments and training materials as well as supervising data collection activities for telephone and field surveys. She also has acted as the translation reviewer of Spanish documents for numerous RTI surveys and has trained Spanish-speaking bilingual interviewers. Prior to working on the NHSDA, Ms. Hinsdale served as Project Director for the National Hispanic Enumeration Survey, a national study conducted annually since 1994 for a commercial client. Ms. Hinsdale earned her B.A. in Sociology and Spanish from the University of North Carolina at Chapel Hill.

Guillermina (Willie) Jasso, Ph.D. is Professor of Sociology at New York University. Her major research interests are justice analysis, international migration, mathematical models for theory building, and factorial survey methods for empirical analysis. Dr. Jasso received her Ph.D. at The Johns Hopkins University in 1974. Since then she has served on the faculties of Barnard College, Columbia University, the University of Michigan, the University of Minnesota, the University of Iowa, and New York University. Dr. Jasso also served as Special Assistant to the Commissioner of the U.S. Immigration and Naturalization Service (1977-79) and as Director of Research for the U.S. Select Commission on Immigration and Refugee Policy (1979-80). In addition to authoring numerous scientific articles, she has served on many advisory boards. She was a member of the National Academy of Sciences Panel on the Demographic and Economic Consequences of Immigration and of the Core Research Group of the Binational Study of Migration Between Mexico and the United States.

Raynard Kington, M.D., Ph.D. was appointed the Director of the NIH Office of Behavioral and Social Sciences Research in 2000. Prior to this, he was the Director of the Division of Health Examination Statistics at the National Center for Health Statistics. In that capacity, he served as Director of the National Health and Nutrition Examination Surveys, the only nationally representative study of the health of the American people based on clinical examination and biologic specimens. He has also been a Senior Scientist in the Health Program at RAND, where he was Co-Director of the Drew/RAND Center on Health and Aging, a National Institute on Aging Exploratory Minority Aging Center. Dr. Kington received his B.S. (with distinction) and his M.D. from the University of Michigan, completed his residency in Internal Medicine at Michael Reese Medical Center in Chicago, and was appointed a Robert Wood Johnson Clinical Scholar at the University of Pennsylvania. While at the University of Pennsylvania, he completed his M.B.A. (with distinction) and his Ph.D. with a concentration in Health Policy and Economics at the Wharton School. He is board-certified in Internal Medicine, Geriatric Medicine, and Public Health and Preventive Medicine.

Rose Maria Li, M.B.A., Ph.D. is Chief of the Population and Social Processes Branch, and Deputy Director of the Office of Research Resources and Development, Behavioral and Social Research Program, National Institute on Aging (NIA), National Institutes of Health. She is responsible for the scientific management of domestic and international research activities in the areas of demography, economics, population epidemiology, and health services. She is currently focusing in particular on a number of special areas of emphasis: health, work, and retirement; health disparities; healthy life expectancy; and linkages between early life influences and later life health. Dr. Li came to the NIA in her current capacity in June 1999. Previously, she was a Program Officer with the Demographic and Behavioral Sciences Branch of the National Institute of Child Health and Human Development (NICHD). Dr. Li received her Masters in Business Administration from the University of Chicago in 1986 and earned her doctorate in Public and International Affairs from Princeton University in 1992, with a concentration in Population Policy.

Yvonne Maddox, Ph.D. was named Deputy Director of the National Institute of Child Health and Human Development in January 1995. She is also currently serving as the Acting Deputy Director of the National Institutes of Health (NIH). Dr. Maddox received her doctorate in physiology and biophysics from Georgetown University, and has had a wide array of biomedical research and teaching experiences. Throughout her academic and Government career, Dr. Maddox has been recognized as a champion of women's issues. She plays a vital role in the identification of issues related to women as scientists and as participants in research studies at the NIH level as well as at the U.S. Department of Health and Human Services level. She is guiding new approaches to funding research on innovative high priority areas.

Patricia Maher, Ph.D. is the Associate Director for Data Collection and Processing Services in the Division of Surveys and Technologies at the University of Michigan Institute for Social Research (ISR). In her current position, she is responsible for the management and implementation of the Early Childhood Longitudinal Study, Kindergarten Cohort, as well as coordinating the data collection operations within the Division of Surveys and Technologies. She has more than 10 years of experience participating in and managing complex and large-scale data collection surveys. Dr. Maher has been with ISR since 1988, beginning her work in the centralized Telephone Center by recruiting, hiring, training, and managing staff.

Peggy McCardle, Ph.D., M.P.H. is the Associate Chief of the Child Development and Behavior Branch of the National Institute of Child Health and Human Development, at the National Institutes of Health. In addition to her branch administrative duties, she is director of the research program on Language, Bilingualism and Biliteracy Development and Disorders. Dr. McCardle holds a Ph.D. in linguistics from the Pennsylvania State University, an M.P.H. from the Uniformed Services University of the Health Sciences in Bethesda, MD, and certification in speech-language pathology from the American Speech-Language-Hearing Association. Dr. McCardle serves as the Institute liaison to the National Reading Panel, in addition to leading the development of several new initiatives in literacy, including the formation of the Biliteracy Research Network, which currently consists of approximately five million dollars of NICHD-Department of Education jointly funded research on the development of English literacy in children whose first language is not English.

James W. McNally, Ph.D. is a Senior Research Associate at the Institute for Social Research at the University of Michigan, Ann Arbor. He is also the Project Manager for the National Archive of Computerized Data on Aging, which is located with the Inter-University Consortium for Political and Social Research at the University of Michigan. His research interests are largely focused on survey methodology and the use of large data sets for secondary analysis. He has worked with a number of longitudinal data sets related to aging including SIPP, LSOA and NLTCS as well as census data and cross-sectional surveys from a variety of countries. He is particularly interested in the repair and enhancement of data and has worked on a variety of imputation strategies. Dr. McNally has also done work on migration and public health in the United States, Vietnam, Fiji, and the Philippines. Dr. McNally received his B.A. in Anthropology from the University of Maryland, College Park, his M.A. in Applied Demography from Georgetown University, and his Ph.D. in Demography and Sociology from Brown University.

Thomas E. Perez, J.D., M.P.P. was appointed Director of the Office for Civil Rights (OCR) for the U.S. Department of Health and Human Services on February 16, 1999. As Director of OCR, Perez is responsible for ensuring that programs and activities receiving funds from HHS are in compliance with all civil rights laws. Prior to this appointment, Mr. Perez served at the Department of Justice as Deputy Assistant Attorney General for Civil Rights, from January 1988 to February 1999. Mr. Perez received an A.B. in International Relations-Political Science from Brown University in 1983, a J.D. cum laude in 1987 from Harvard Law School, and a Master's in Public Policy from the John F. Kennedy School of Government in 1987.

John Ruffin, Ph.D. was appointed the first Director of the National Center on Minority Health and Health Disparities at the National Institutes of Health (NIH) on January 9, 2001. In this role he leads a national program of biomedical research, training and dissemination of information on health conditions disproportionately affecting racial and ethnic minorities and other medically underserved populations. Dr. Ruffin is the former Director of the NIH Office of Research on Minority Health, NIH. A native of New Orleans, Louisiana, Dr. Ruffin received his B.A. from Dillard University and a Master's degree from Atlanta University. He earned a Ph.D. at Kansas State University in systematic and developmental biology and then pursued postdoctoral studies at Harvard University. Prior to joining the NIH, he was Dean of the College of Arts and Sciences at North Carolina Central University.

Robert L. Santos, M.A. is currently the Executive Vice President and Partner at NuStats Partners, LP in Austin Texas. He previously held the position of Principal Research Associate at The Urban Institute in Washington, D.C, and Vice President of the Statistics and Methodology Division in the National Opinion Research Center at the University of Chicago. Mr. Santos has more than 20 years of experience in the survey research industry as a sampling statistician, statistician, project director, and senior research administrator. He specializes in survey methodology, survey design, and rare element sample designs, especially designs related to Hispanic or other minority groups. He is a member of the Editorial Board of the Public Opinion Quarterly, holds office as Secretary-Treasurer of AAPOR, is a member of the Census Advisory Committee of Professional Associations, and holds other offices and committee memberships in the American Statistical Association.

Gillian Stevens, Ph.D. is Associate Professor of Sociology at the University of Illinois at Urbana-Champaign. Her research interests concern immigration and language. She has published articles on patterns of ethnic, racial, and linguistic intermarriage, and on patterns of language usage, language shift, and English acquisition among immigrants in the United States. Dr. Stevens received her Ph.D. in Sociology from the University of Wisconsin-Madison.

Nathan Stinson, M.D., Ph.D., M.P.H. became the Deputy Assistant Secretary for Minority Health and the Director of the Office of Minority Health on August 2, 1999. As Deputy Assistant Secretary, Dr. Stinson reports to the Assistant Secretary for Health/Surgeon General and works closely with all agencies throughout the Department of Health and Human Services (DHHS). Under Dr. Stinson's leadership, the Office of Minority Health develops and coordinates Federal health policy that addresses minority health concerns and ensures that Federal, State, and local health programs take into account the needs of disadvantaged, racial and ethnic populations. Dr. Stinson also oversees regional minority health consultants at the ten DHHS regional offices. Dr. Stinson received his B.A. from the University of Colorado, his master's degree from the University of California, and his Ph.D. from the University of Colorado—all in Environmental Biology. He received his M.D. from the University of Colorado Medical School, and his M.P.H. in Health Care Administration from the Uniformed Services University of Health Sciences.

Katherine Wallman currently serves as Chief Statistician at the U.S. Office of Management and Budget. In this capacity she is responsible for overseeing and coordinating Federal statistical policies, standards, and programs; developing and fostering long-term improvements in Federal statistical activities; and representing the Federal Government in international organizations such as the United Nations Statistical Commission. Prior to assuming this position, Ms. Wallman served for more than a decade as Executive Director of the Council of Professional Associations on Federal Statistics, a coalition of organizations concerned with fostering communication among users and producers of Federal statistics and improving the utility and accessibility of the Nation's statistical resources. Her special interests include fostering improved dissemination of and access to Federal statistical information, increasing cooperation between the several levels of government in the production of national statistics, strengthening the interface between academic and government statisticians, and enhancing the statistical literacy of the public.

Appendix D. Workshop Participants

Christine Bachrach, National Institute of Child Health and Human Development
Wendy Baldwin, Office of Extramural Research, NIH
Angela Caroline Bates, Office of Research on Women's Health, NIH
Daniel Berch, National Institute on Aging
Richard L. Bitzer, U.S. Census Bureau
Carol Briggs, U.S. Census Bureau
Debra Brody, Centers for Disease Control and Prevention
Natasha Cabrera, National Institute of Child Health and Human Development
Virginia Cain, Office of Behavioral and Social Sciences Research, NIH
Alfredo Calvillo, Centers for Disease Control and Prevention
Olivia Carter-Pokras, Office of Minority Health, Office of the Assistant Secretary for Health
Yinong Chong, National Health and Nutrition Examination Statistics
Centers for Disease Control and Prevention
Rebecca L. Clark, National Institute of Child Health and Human Development
Craig Coelen, National Opinion Research Center, University of Chicago
Kelly Jones Dresen, Translation and Interpretation Department
Comprehensive Language Center, Inc.
Brad Edwards, Early Childhood Longitudinal Study Birth Cohort, Westat
Sumru Erkut, Center for Research on Women, Wellesley College
Robert Frederking, Language Technologies Institute, Carnegie Mellon University
Marilyn Gaska, Lockheed Martin Federal Systems/Owego
David Haines, Departments of Sociology and Anthropology, George Mason University
J. Taylor Harden, National Institute on Aging
Marjorie Hinsdale, National Household Survey on Drug Abuse, Research Triangle Institute
Michael W. Horrigan, National Longitudinal Survey Program, Bureau of Labor Statistics
Guillermina Jasso, Department of Sociology, New York University
Joel Kennet, National Center for Health Statistics, Centers for Disease Control and Prevention
Raynard Kington, Division of Health Examination Statistics, Centers for Disease Control and Prevention
Rose Maria Li, National Institute on Aging
Yvonne Maddox, Office of the Director, NIH and National Institute of Child Health and Human Development
Patricia Maher, Survey Research Center, University of Michigan
Edith McArthur, Office of Educational Research and Improvement
National Center for Education Statistics
Peggy McCardle, National Institute of Child Health and Human Development
James McNally, The National Archive of Computerized Data on Aging
University of Michigan

Richard Nakamura, National Institute of Mental Health
Thomas E. Perez, Office for Civil Rights, U.S. Department of Health and Human Services
Michael Pergamit, Economic Studies, National Opinion Research Center
John Ruffin, Office of Research on Minority Health, NIH
Robert L. Santos, Urban Institute
Susan Schechter, Statistical Policy Office, Office of Management and Budget
Belinda Seto, Office of Extramural Research, NIH
Gillian Stevens, Department of Sociology, University of Illinois at Urbana-Champaign
Nathan Stinson, Office of Minority Health, Office of the Assistant Secretary for Health
Richard Suzman, National Institute on Aging
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